

Internal Rules Council of National Alliances (CNA)

Since its creation, EURORDIS has encouraged and supported the creation of National Alliances for Rare Diseases progressively in all EU member states and beyond. Currently, there are 32 National Alliances who are members of EURORDIS, of which 29 form the European Network of National Alliances for Rare Diseases. The latter are all organisations recognised as “National Alliances of Rare Disease Patient Organisations” by the EURORDIS Board of Directors. The European Network of National Alliances for Rare Diseases is governed by the Council of National Alliances.

The European Network of National Alliances for Rare Diseases aims to foster the visibility and recognition of National Alliances, to take the patient voice to a higher and stronger level, to enhance EURORDIS’ outreach to local patient groups to build a pan-European community of people living with rare diseases, to strengthen rare disease patient group capacities as well as to empower patient advocates.

As part of its mission to build a strong pan-European community of patient organisations and to develop a broader grassroots patient-centred community, EURORDIS has set up the goal (as detailed in the EURORDIS Strategy 2010-2015) to develop more supportive capacity building relationships with its members, including intensifying capacity-building and networking with and between the National Rare Disease Alliances to improve efficacy.

To this end, EURORDIS and the National Alliances have developed a shared process that aims to promote greater convergence and collaboration between National Alliances themselves, and between National Alliances and EURORDIS, through their Strategies and Annual Work Plans, as well as their Strategic Partnerships for an optimal synergy. This shared process is referred to “Common Goals & Mutual Commitments between National Alliances in Europe and EURORDIS: An agenda between 2014 & 2020”.

Eligibility criteria for a National Alliance to be recognised by EURORDIS:

To be recognised as a National Alliance in Europe an organisation must:

1. Firstly, be a full member of EURORDIS:
 - Rare disease organisation according to EU prevalence criteria (5 / 10 000);
 - Organisation from a European country;
 - The Governing Boards should be made up of a majority of rare disease patients, parents or close relatives of patients;
 - Financial independence, particularly from the pharmaceutical industry (max. 50% of funding, from several companies.);
 - Non-profit status;
 - Proven patient support and/or advocacy and/or research activities

2. Secondly, comply with the four following criteria:

- Represent rare disease organisations from a wide range of diseases in at least three groups of diseases (such as immunology, oncology, cardiovascular, infectious, metabolic, neuromuscular, etc.),
- Federate patient organisations from their European country,
- Have a significant number of members, compared to the number of patient groups existing in their country, with clear membership rules,
- Agree to and sign the “Common Goals & Mutual Commitments between National Alliances in Europe and EURORDIS: An agenda between 2014-2020”.

A National Alliance in Europe recognised by EURORDIS automatically becomes a member of the European Network of National Alliances for Rare Diseases and a member of the Council of National Alliances.

EURORDIS may develop a relation with National Alliances not fulfilling all criteria, in which case they are recognised as Associate Members to the CNA. This applies in particular to National Alliances newly established in Europe and to Regional Alliances.

National Alliances based outside Europe can apply to join the CNA as observers.

While the National Alliances encourage their members to become full members of EURORDIS, some patient groups may choose not to apply for membership and consider themselves represented indirectly through their Alliance.

General Objectives of the Council of National Alliances (CNA):

The Council of National Alliances is defined in the by-laws of EURORDIS, article 10-1, as adopted at the Annual General Assembly on 24 May 2003 in Namur, Belgium.

The major tasks of the Council, as expressed in the EURORDIS by-laws, are:

- i) to strengthen the European Network of National Alliances,
- ii) to participate in relevant EURORDIS activities,
- iii) to provide advice and expertise to the Board of Directors.

Each National Alliance regularly provides information about their governance, membership, strategies & work plans, budget & financial resources, human resources, strengths & weaknesses; key common indicators will be developed; each Alliance will provide EURORDIS with a regularly updated list of their members (including website addresses).



EURORDIS provides information such as the Newsletter or internal memos to National Alliances, which they will do their best to translate and disseminate to their members.

The National Alliances provide information about RD policy from their respective countries. EURORDIS summarises this update in English and disseminates this information among the National Alliances.

In order to promote greater convergence and collaboration between National Alliances and between National Alliances and EURORDIS, the Council of National Alliances and EURORDIS have developed the “Common Goals & Mutual Commitments”, which is signed by all National Alliances. A non-binding Annex provides an Implementation Plan which is governed by the Council of National Alliances.

The Council provides advice to the EURORDIS Board of Directors on various relevant topics at Council or Board initiatives.

Organisation

The Council of National Alliances is made up of representatives from National Rare Disease Alliances.

Each National Alliance appoints a representative and an alternate to the Council for a two-year renewable period. This representative is the contact person for EURORDIS, and must be committed to attending all CNA meetings, and to keeping the alternate up-to-date on all CNA activities in case of the representative’s unavoidable absence.

The Council of National Alliances holds at least one workshop a year. The date of this workshop is announced at the latest three months in advance. The agenda of the workshop is disseminated at least four weeks in advance following a two week consultation period during which the CNA is invited to propose items for the agenda.

At this workshop the National Alliances exchange their experiences in the approach to different issues concerning rare diseases and collaborates on common goals such as Rare Disease Day and National Plans.

Regular conference calls / webinars are organised on specific topics when needed. The CNA organises working groups where necessary to take charge of specific objectives such as Rare Disease Day, European Year of Rare Diseases, Organising Committee of the European Conference on Rare Diseases.

All CNA decisions are made by consensus, to the extent that this is possible. If consensus is not reached, diverging opinions are accepted and recorded accordingly.

General financial guidelines

EURORDIS will cover the cost of preparing CNA workshops, meeting rooms and meals.

Each National Alliance will pay for its representative's travel and lodging. Meetings and Workshops can take place in different countries over time.

National Alliances can apply for the *National Alliances Exchange Program-Learning from Each Other*, which is an exchange Program for National Alliances in the form of Short Term Fellowships to enable more direct exchange, transfer of knowledge and collaboration between one National Alliance with another and to offer means of mutual support and capacity building.

With the support of:

